The Report Committee for Susannah Townsend Plocher
Certifies that this is the approved version of the following report:

Improving End-of-Life Care

APPROVED BY
SUPERVISING COMMITTEE:

Supervisor:

Todd Olmstead

Barbara Jones

Improving End-of-Life Care

by

Susannah Townsend Plocher, B.A.

Report

Presented to the Faculty of the Graduate School of

The University of Texas at Austin

in Partial Fulfillment

of the Requirements

for the Degrees of

Master of Public Affairs

And

Master of Science in Social Work

The University of Texas at Austin

August 2016

Abstract

Improving End-of-Life Care

Susannah Townsend Plocher, M.P.Aff. /M.S.S.W.

The University of Texas at Austin, 2016

Supervisor: Todd Olmstead

The purpose of this report is to examine our attitudes towards end-of-life care and assess the systems of reimbursement and quality measurement that support and sustain it. This report is divided into two primary sections: the first, Culture, explores the culture of end-of-life care, from its historical roots and development to its slow integration into modern medicine. The second, Infrastructure, focuses on the Medicare Hospice Benefit and quality measurement under the Affordable Care Act. Under healthcare reform, reimbursement is now more than ever tied to quality and as such the two systems operate in close concert. Their influence on the provision and assessment of end-of-life care is significant, and this report analyzes flaws in each that undermine their potential to truly advance quality, person-centered care. This report ends with recommendations for improvement for both reimbursement and quality measurement, with the sincere hope that by strengthening the structures that support end-of-life care, we will better support patients and their families.

Table of Contents

Introduction

The realization that we each will die comes, for many, with a natural impulse to push that reality away. We focus instead on the here-and-now, we count our blessings, we live our lives, and we move the business of our ending to a later date. The story of hospice and palliative care's development in the United States is really no different. A late arrival to our shores, an outgrowth of a faith-based tradition of service, the question of how we treat our dying has really only taken root in the last thirty years. Since then, growth has been slow. Individuals, care providers, and policymakers have made incremental movement towards a more open consideration of care at end of life; how with advance planning and open communication, the process of dying does not have to be something merely to fear, but an opportunity to spend quality time, free of pain and suffering, with those you love.

What this report seeks to do is better understand our attitudes towards end-of-life care and analyze the systems that structure and sustain it. Section one – Culture – explores the historical roots of end-of-life care and its development in the United States, and considers its halting integration into the mainstream due to traditions of medical culture and our deference to them. Understanding the changing attitudes towards death and dying sheds light on the common resistance of both individuals and their care providers to face death, as they pursue continued treatment even when the evidence-based benefits of hospice and palliative care are clear. Revealing the human experience of

needing (or needing to provide) end-of-life care provides the human framework for an analysis of the policies that give individuals access to it.

Section two – Infrastructure – examines the two primary supports of end-of-life care: first, the mechanism that pays for it (reimbursement), and second, the evaluative measures that ensure its quality. Insurance reimbursement deeply influences patient enrollment patterns, provider demographics, and the services they deliver, while quality measurement theoretically ensures accountability for the services provided and paid for by insurance. As the Affordable Care Act seeks to transition the American medical system from fee-for-service to pay-for-performance, now more than ever is quality tied to reimbursement and as such, they stand in close connection. Together they deeply influence how end-of-life care is delivered, monitored, and sustained, and any effort to understand our personal or cultural reticence to discussing options at end of life is futile without also analyzing the policies that make those options available to us.

An effort to understand end-of-life care, from history to culture, from person to provider, from mythmaking to policy, is an effort to understand how the experience of dying has become what it is, and to use that knowledge to consider and recommend a better path forward.

I. CULTURE

Death Panels

Late summer of 2009 marked the opening movement of what would become – and in many ways, remains – a fierce debate about the intent and values of national healthcare reform. One month after Speaker of the House Nancy Pelosi introduced the Affordable Health Care for America Act (H.R. 3962), and as the Senate moved to introduce its version, America's Healthy Future Act (S.1796), Sarah Palin, the former governor of Alaska and failed vice presidential candidate, published on Facebook a "Statement on the Current Health Care Debate." She wrote:

> As more Americans delve into the disturbing details of the nationalized health care plan that the current administration is rushing through Congress, our collective jaw is dropping, and we're saying not just no, but hell no!
>
> The Democrats promise that a government health care system will reduce the cost of health care, but as the economist Thomas Sowell has pointed out, government health care will not reduce cost; it will simply refuse to pay the cost. And who will suffer the most when they ration care? The sick, the elderly, and the disabled, of course. The America I know and love is not one in which my parents or my baby with Down Syndrome will have to stand in front of Obama's "death panel" so his bureaucrats can decide, based on a subjective judgment of their "level of productivity in society," whether they are worthy of health care. Such a system is downright evil.
>
> Health care by definition involves life and death decisions. Human rights and human dignity must be at the center of any health care discussion.[1]

Palin's statement was directed at her base of small-government conservatives, speaking directly to their fears of encroachment by federal powers. Raising the specter of socialism through repeated emphasis on the "nationalizing" of healthcare, Palin's words

[1] Palin, "Obama and the Bureaucratization of Health Care."

served as a powerful voice against reform. Riding a wave of fame, albeit on the decline, from the 2008 presidential election, Palin had a pulpit from which she could influence the dialogue. Statements such as those she posted in 2009, and the many that followed, shaped public perception both on the reform's ideological intent as well as its practical implications.[2]

Nowhere was this clearer, or more damaging, than in her 2009 introduction of "death panels." A reincarnation of earlier statements made by the conservative commentator Betsy McCaughey[3], Palin's "death panels" referred to a specific section of the house bill that would have allowed Medicare coverage for "voluntary advance care planning" sessions during annual well visits.[4] In her comments, Palin also drew attention to the proposed formation of the Independent Medicare Advisory Council, a five-member committee whose formation would serve as a formal body to issue Medicare cost saving recommendations to the president. Palin characterized this council as judges on the death panels:

> [A]n unelected, largely unaccountable group of experts charged with containing Medicare costs… who would guide decisions regarding that [quoting President Obama] 'huge driver of cost… the chronically ill and those toward the end of their lives.' Given such statements, is it any wonder that many of the sick and the elderly are concerned that the Democrats' proposals will ultimately lead to rationing of their health care by – dare I say it – death panels?"[5]

---

[2] Belluck, "Coverage for End-of-Life Talks Gaining Ground."; Weiner, "Sarah Palin Suggests Coin Conspiracy."

[3] In an interview in July 2009, McCaughey was quoted as saying that Medicare will now have a "required counseling session that will tell [people] how to end their life sooner, how to decline nutrition, how to decline being hydrated, how to go in to hospice care." Nyhan, "Why The 'Death Panel' Myth Won't Die," 10.

[4] Belluck, "Coverage for End-of-Life Talks Gaining Ground."

[5] Palin, "Obama and the Bureaucratization of Health Care."

In Palin's view, there appeared a conflict between the Council's task to control costs with the role of government to protect and provide for its people. To Palin – and her many supporters – death panels proved that the ideological goal of reform (and 'big' government, more generally) was to decrease financial cost no matter the human cost. It was, in essence, not to reform care, but to remove those who needed it most.

Palin's charges were ultimately debunked by those across the political spectrum. However, the idea became a lightening rod for criticism of the Affordable Care Act (ACA) and shifted the conversation from what reform could achieve to how it signaled heartless cost cutting and government overreach.[6] Indeed, a Pew study in late August of 2009 found that 86% of Americans reported that they had heard the legislation "includes the creation of so called 'death panels' or government organizations that will make decisions about who will and will not receive health care services when they are critically ill," and of those, 30% believed it was true and 20% did not know.[7] Regardless of its eventual discrediting, Palin's "death panels" helped drive a wave of opposition against reform efforts, ultimately forcing the Obama administration to withdraw the provision from the ACA's final language.[8]

The story of Sarah Palin's "death panels" begins this paper because it captures the toxicity surrounding the ACA and its herculean task of reform, as well as more generally the damaging mythmaking that too often shapes policy decisions. It also speaks to the

---

[6] Belluck, "Coverage for End-of-Life Talks Gaining Ground."; Weiner, "Sarah Palin Suggests Coin Conspiracy."
[7] Nyhan, "Why The 'Death Panel' Myth Won't Die," 12.
[8] Belluck, "Coverage for End-of-Life Talks Gaining Ground."; "10 FAQs: Medicare's Role in End-of-Life Care."

visceral discomfort that remains around discussions of death and the care we provide at end of life. In addition to the personal discomfort death may cause, resistance is even greater to the idea that someone else – let alone government – may play a role in our decision making. It is not surprising that supporters of Palin seized on the proposal as the purest sign of government overreach, but death reaches across the aisle and we are each of us confronted with the question of what good care and the right decisions will look like for us at end of life. Indeed, the breadth and ferocity of the response to "death panels" speaks to the emotion that is shared when we consider our lives at its close.

Looking Back at End of Life

The resistance to discussing end of life is rooted, in no small part, in the development of end-of-life care. Prior to the technological advancements of the 20th century, death was common and occurred largely at home: either from death in childbirth or from diseases like tuberculosis, most families knew death and in its commonality it was neither taboo nor hidden from the community. In fact, "the collective reaction was to keep the dying person involved in everyday life until the end."[9] In the beginning decades of the 20th century, however, as medical treatments increased and hospital technology became more advanced, "the beginning of the lie" was born: death was no longer something you had to accept, but something you could fight. Individuals who would previously have been in the community, made comfortable while dying surrounded by friends and family (and friends and family, in turn, made more comfortable with dying), were now removed from the communal space. Sick individuals were moved into hospitals and other such care facilities, and the communities they left behind began to lose touch with the experience.[10]

While "it is hard to imagine that we will ever return to the public interaction with death typical of past centuries," models of care have since been developed which seek to return the dying to their communities – the primary of which being hospice.[11] Though hospice did not enter the mainstream until the later part of the 20th century, its roots are in

[9] Niethammer, *Speaking Honestly*, 35.
[10] Ibid, 36.
[11] Ibid, 37.

fact medieval.[12] The word hospice derives from the Latin word 'hospes,' which refers to a traveling guest or traveler's host. Hospice homes were first established in the 11th century, and were managed by religious orders to provide care for dying travelers and crusaders.[13] Though hospices came and went in parallel with the orders who ran them, their more formal establishment did not occur until the late 19th century with the founding of St. Joseph's Hospice in London, which is credited with birthing the modern hospice concept.[14] Some decades later, Dame Cicely Saunders, a British nurse and social worker, began volunteering at another London hospice, St. Luke's Home for the Dying Poor. Her work there inspired her to pursue a medical degree with a focus on palliative care.[15] Dame Saunders ultimately developed the core concepts of hospice care that include: "1) the concept of 'total pain,' including physical, spiritual, and psychological discomfort; 2) the proper use of opioids for patients with physical pain; and 3) attention to the need of family members and friends who provide care for the dying."[16] These central tenets describe a holistic perspective of end-of-life care that supports the entire individual, and remains the cornerstone of hospice and palliative practice today.

It was not until the mid-1960s that a series of events drew attention in the United States towards the care at end of life. In 1963 Dame Saunders was invited to lecture at Yale University about her work, followed in 1969 by the publication of *On Death and*

---

[12] Pyenson et al., "Medicare Cost in Matched Hospice and Non-Hospice Cohorts," 201.; Morden et al., "End-of-life Care for Medicare Beneficiaries," 793.
[13] Lutz, "The History of Hospice and Palliative Care," 305; Hashe, "Being There for Those at End-of-Life."
[14] Lutz, "The History of Hospice and Palliative Care," 305.
[15] Lutz, "The History of Hospice and Palliative Care," 305.; "Hospice Background."
[16] Ibid.

Dying by the famed Swiss-American psychiatrist, Elizabeth Kubler-Ross. *On Death and Dying* introduced the concept of the five stages of grief that patients experience when dying, and it advocated for the importance of home care and the voice of the individual in their care.[17] The topic received further attention when Kubler-Ross testified before the Senate Special Committee on Aging, saying:

> We live in a very particular death-denying society. We isolate both the dying and the old, and it serves a purpose. They are reminders of our own mortality. We should not institutionalize people. We can give families more help with home care and visiting nurses, giving the families and the patients the spiritual, emotional, and financial help in order to facilitate the final care at home.[18]

Kubler-Ross' words spoke to the historical movement of death from home to hospital, taking with it our understanding of, and comfort with, care for those at end of life. Rather than institutionalizing them – moving them out of our sight, largely for our own comfort – Kubler-Ross called on the community to think about the holistic wellness of the dying and how we can better honor them. Inspired by her work and the leadership of Dame Saunders, and further promoted by the national interest in cancer that was gaining speed around the same time, the United States' first hospice was opened in 1973.[19]

---

[17] Lutz, "The History of Hospice and Palliative Care," 305; Hashe, "Being There for Those at End-of-Life."; "Hospice Background."
[18] "Hospice Background."
[19] Jennings, Ryndes, D'Onofrio, and Baily, *The Hastings Center*, 6.

Hospice and Palliative Care

One of the biggest barriers to support of hospice and palliative care is the persistent belief that they operate solely in the business of death and dying. A lack of understanding about the spectrum of services that end-of-life care provides keeps many from attaining the higher quality, and even quantity, of life they seek for themselves or their loved ones.

Hospice is a model of care provided to those with an advanced, terminal illness, commonly with a prognosis of six months or less to live. Hospice utilizes supportive – not curative – interventions to ensure quality of life, psychosocial and emotional support, and pain and symptom management. Hospice services include: nursing care, personal assistance with daily living, rehabilitation, counseling, dietary support, prescription assistance, and respite and other family services (among many others).[20] Provided by an interdisciplinary team of doctors, nurses, social workers, specialists, and case managers, the hospice model relies on healthcare teams working together to support the "whole person," which includes their family and community.[21]

Palliative care likewise focuses on symptom management and quality of life; however, patients who are ill can access palliative services without a terminal diagnosis

[20] Huskamp et al., "Variation in Patients' Hospice Costs," 234.; Nakhoda, "End-of-life Care and the Medicare Hospice Benefit," 25.
[21] Jennings, Ryndes, D'Onofrio, and Baily, *The Hastings Center,* 6.; Nakhoda, "End-of-life Care and the Medicare Hospice Benefit," 25.

and can use it alongside curative interventions.[22] Palliative "cover[s] all forms of the prevention and treatment of suffering," where hospice focuses more on the final stages of life.[23] Palliative care was developed as an outgrowth of hospice care, utilizing an interdisciplinary care team to meet the gaps in hospice by focusing on patients who, though not actively dying, suffer from a chronic or complex illness that may result in burdensome symptoms.[24] While hospice is provided outside the hospital setting, palliative care is today integrated with inpatient services at most major hospitals. True to the teachings of Dame Saunders and the faith-based leaders before her, both hospice and palliative care are deeply informed by the ethics of compassion, dignity and service.[25]

Though in its first decades of practice in the United States, hospice predominantly served white, middle and upper class patients, end-of-life care has grown to include palliative services and together they serve a broader range of patients and diagnoses.[26] Currently in the United States, there are 2.5 million deaths each year, of which 50% occur in a hospital or care setting, and 38% of those dying from 'anticipated death' received hospice.[27] Use of hospice has continued to grow, with 496,000 enrollees in 1997 growing to over 1.6 million in 2012. While cancer remains the primary diagnosis for patients on hospice (44%), improvements in cancer care and increasing knowledge of other chronic

---

[22] Jennings, Ryndes, D'Onofrio, and Baily, *The Hastings Center,* 7.; Himelstein, Hilden, Boldt, and Weissman, "Pediatric Palliative Care," 1752.; Hartjes, "Making the Case for Palliative Care," 291.
[23] Ibid.
[24] Himelstein, Hilden, Boldt, and Weissman, "Pediatric Palliative Care," 1752.
[25] Jennings, Ryndes, D'Onofrio, and Baily, *The Hastings Center,* 6.
[26] Ibid.
[27] Ibid, 11.

and complex illnesses such as Alzheimer's continue to change the demographics of hospice use.[28]

The benefits of end-of-life care to patients and caregivers are well documented in research. A wide range of studies show how hospice and palliative care help patients avoid invasive interventions at end of life which, however much they may extend life, do little to increase its quality. Gozalo et al. found that Medicare beneficiaries on hospice had a larger reduction in aggressive end of life interventions and a decreased rate of intensive care unit (ICU) admissions in the last thirty days of life, and experienced other positive outcomes like decreases in feeding tube insertions and "burdensome transitions" between care facilities.[29] Obermeyer et al. identified "statistically significant" differences between hospice users and those without, finding that those without hospice had more hospitalizations for acute conditions and medical comorbidities, and had higher use of the ICU and other invasive procedures.[30] Overall, researchers have found that patients receiving end-of-life care have fewer physical symptoms, improved mood, and a more accurate understanding of their prognosis.[31] For families, hospice and palliative care have

---

[28] American Society of Clinical Oncology, "The Debate in Hospice Care," 154.; "Hospice Care in America."

[29] ICU admissions reflect poor symptom management and high pain, which are markers of poor quality care and low satisfaction at end of life (which palliative and hospice care are demonstrated to help ameliorate). Gozalo et al., "Changes in Medicare Costs With The Growth of Hospice Care in Nursing Homes," 1829.

[30] Obermeyer, et al., "Association Between the Medicare Hospice Benefit and Health Care Utilization," 1893.

[31] Kang et al., "Integration of Palliative Care," 320.; Hartjes, "Making the Case for Palliative Care," 209.

also "been shown to reduce both the incidence of aggressive intervention and the subsequent psychological stress among surviving family members."[32]

While those unfamiliar with end-of-life care may associate it with death and dying, building evidence shows that it can, in fact, even extend life as individuals forgo the toxicity and intensity of interventions in favor of focusing on quality of life and building psychosocial supports around them.[33] Among many studies highlighting this phenomenon, a 2007 report from the *Journal of Pain and Symptom Management* found that hospice patients lived 29 days longer than their non-hospice counterparts. In another study from 2010 from the *New England Journal of Medicine*, it found that patients with non-small-cell lung cancer in fact lived longer with hospice care.[34]

For hospital administrators and payors there are substantial benefits as well. By enrolling patients in supportive end-of-life care, hospitals find significant savings from patients' overall shortened length of stay and fewer admissions to the ICU, in addition to decreased "bounce back" admissions (when the patient returns within 30 days, for which many hospitals are penalized under the ACA's pay-for-performance metrics).[35] One study found that hospice saved payors $700 per day per bed by keeping patients out of critical care beds. Savings to patients were also generated from averted co-pays from forgoing unnecessary physician office visits.[36] In an early meta-analysis of healthcare

---

[32] Wessman, Sona and Schallom, "Improving Caregivers' Perceptions," 2.; Hartjes, "Making the Case for Palliative Care," 209.
[33] Pyenson et al., "Medicare Cost in Matched Hospice and Non-Hospice Cohorts," 201.; Morden et al., "End-of-life Care for Medicare Beneficiaries," 793.
[34] American Society of Clinical Oncology, "The Debate in Hospice Care," 153.
[35] Passik et al., "Is There a Model for Demonstrating a Beneficial Financial Impact," 420.
[36] Edens, Harvey and Gilden, "Developing and Financing a Palliative Care Program" 381.

savings from 1996, it found that hospice saved up to 40% of healthcare costs during the patient's last month of life, and 17% of those in the last six months. These findings were echoed over a decade later, in a 2007 study that found reduction in Medicare costs during the last year of beneficiaries' lives of $2,309 per hospice enrollee.[37]

End-of-life care supports decreased interventions; as such, it does not generate revenue and is therefore often difficult to sell to hospital administrators.[38] However, by facilitating care diversion it helps people stop unnecessary, expensive interventions that hospitals then must meet the cost of providing.[39] Despite the substantial cost savings, Medicare has also been slow to fully support integrating hospice and palliative care into the medical mainstream. By most estimates, approximately 25% of Medicare spending is on the last year of beneficiaries' lives; however, only 1% of the Medicare budget is allotted for hospice services. This, too, despite studies such as one from 1999, which found that for every $1 spent on hospice, Medicare saved $1.52.[40] Building a body of evidence on the positive impacts of end-of-life care, therefore, is essential for the promotion of hospice and palliative care.

---

[37] American Society of Clinical Oncology, "The Debate in Hospice Care," 154.
[38] Von Gunten, "Financing Palliative Care," 780.
[39] Passik et al., "Is There a Model for Demonstrating a Beneficial Financial Impact," 420.
[40] Nakhoda, "End-of-life Care and the Medicare Hospice Benefit," 25.; Gozalo et al., "Changes in Medicare Costs With The Growth of Hospice Care in Nursing Homes," 1824.

The Culture of Care

Despite the foundational work of pioneers like Saunders and Kubler-Ross, and the increasing body of research that speaks to its wide-ranging benefits as well as cost savings, the acceptance of hospice and palliative care into the mainstream has been slow. This is due in part to the culture of medicine and technology that resists doing anything less than what is possible, the culture of physician authority that has contributed to patients' deference to these tendencies towards intervention, and the cultural aversion to death in general that effectively postpones discussions regarding it.

The roots of physician authority are as ancient as medicine itself: in 129 AD, the Greek physician, Galen, was quoted as saying, "the patient's trust is indispensable for the healing process."[41] Physicians were, and for most of modern history have continued to be, considered of a higher professional class and therefore seldom challenged. It was not until World War II that more open examination of the physician-patient relationship began, as atrocities committed by physicians in concentration camps directly challenged the notion of their unquestionable authority. These inquiries continued in the United States as reports of the sterilization and medical testing of epileptics, the mentally ill, and other stigmatized communities came forward.[42] This period, though painful, allowed for the emergence of the autonomous patient who had more decision-making power. In his book on communicating with dying children, the German writer Dr. Dietrich Niethammer refers to this period as a shift in medical culture from ethics based on responsibility

[41] Niethammer, *Speaking Honestly*, 42.
[42] Ibid, 43.

(doing what you think is best for the patient), to a contract-based ethics (doing what the patient has agreed to do).[43] This allows for a relationship built on trust, where the patient may choose to follow the physician's advice not out of deference, but free will.

The deference to physician authority has long shaped individuals' relationships with their illness and options for care. So, too, has physicians' own inability to face the death of their patients and the limits of medicine. In the days before modern medicine, physicians avoided discussing death from an acknowledgement that in many cases, there was little more they could do than allow the patient hope. In the words of the 19th century German doctor Christoph Wilhelm Hufeland, "He who names death, brings death."[44] In the modern age, physicians have been able to avoid discussing death by focusing instead on the curative capacities of technology. The consequence of technological progress, however, is that no matter the lives it has saved, "it has had the unintended consequence of offering false hope to [patients] that death can always be averted."[45] Death is seen "more as a therapeutic misadventure than as a natural process resulting from a disease," and "recognition that death is inevitable often lags behind the reality of the medical condition, leading to a treatment approach that is inappropriately aggressive."[46]

Data on the interventions that the critically ill and actively dying undergo speak to the extent to which the culture of intervention drives care: in 1996, a study on Medicare beneficiaries dying from cancer found that 22% of patients received a new round of

---

[43] Niethammer, *Speaking Honestly*, 46.
[44] Ibid, 101.
[45] Himelstein, Hilden, Boldt, and Weissman, "Pediatric Palliative Care," 1757.
[46] Ibid.

chemotherapy in their last month of life, and that from 1993 to 1996 treatment within the last two weeks of their life went up by 5%, with similar rates found in those whose cancer was already deemed unresponsive.[47] In a more recent study on ICU admissions at end of life by Rady and Johnson, over 70% received aggressive therapy including life support when their short-term survival rate was less than 50%.[48] This study built on the findings of an earlier one that found that even when patients expressly desired comfort care (symptom management only), physicians still initiated aggressive therapies.[49] As described in the Rady and Johnson study, "the disparity between the type of therapy offered by physicians and the care consistent with patient prognoses has been recognized as a major obstacle to the quality of end-of-life care."[50]

Considering the centrality of intervention to medicine, it is no surprise that hospice and palliative care have been slow to gain traction. As described by the American Society of Clinical Oncology (ASCO), "paradoxically, the very advances in treatment that have enhanced cancer care and survival have created perhaps the most important barrier to the effective use of hospice."[51] For many physicians, hospice and palliative care are viewed as "giving up" on potential life-extending treatments, a threat to their curative powers and those of technology. The little training that medical professionals receive on leading end-of-life care discussions has worsened this resistance. For many, it is also simply too personally difficult to talk to their patients and families about dying when the

[47] Matsuyama, Reddy and Smith, "Why Do Patients Choose Chemotherapy," 3490.
[48] Rady and Johnson, "Admission to Intensive Care Unit," 708.
[49] Ibid, 706.
[50] Ibid, 708.
[51] American Society of Clinical Oncology, "The Debate in Hospice Care," 154.

care relationship has so far been based in curative hopes.[52] A study by Steinhauser et al. on the factors important to patients at end of life found that, "one of the challenges of comprehensive end-of-life care [is] attending to aspects of care that are not intuitively important to clinicians but are critical to patients and their families."[53] This speaks to findings of other studies that have identified patient priorities that do not match their physician's: one study found that patients ranked mental awareness highly whereas doctors were more willing to sacrifice lucidity for pain suppression.[54] Steinhauser et al. continue: "as our cultural lexicon of death and dying expands, further research is needed to define both the common ground and areas for negotiation as participants gather to construct quality at the end of life. A challenge to medicine is to design flexible care systems that permit a variety of expressions of a good death."[55] Supporting physicians to be better participants in this discussion is necessary to support better end-of-life care.

It bears noting that while physician resistance to discussing death is a substantial barrier to timely discussions of end-of-life care, patients can, and often do, contribute to the extension of interventions past the point of effectiveness. The principle that "medicine, and more broadly science, delivers the goods," is driven in large part by the comfort that certainty brings.[56] When faced with illness, patients seek hope; tests and procedures help alleviate the anxieties of a poor or uncertain prognosis. As described by

---

[52] Wessman, Sona and Schallom, "Improving Caregivers' Perceptions," 2.; Steinhauser et al., "Factors Considered Important," 2476.; Matsuyama, Reddy and Smith, "Why Do Patients Choose Chemotherapy," 3491.
[53] Steinhauser et al., "Factors Considered Important," 2481.
[54] Ibid.
[55] Ibid, 2482.
[56] Hobson, "Why Do Patients Want Treatment That Doesn't Work?"; Detsky, "What Patients Really Want from Healthcare," 2500.

Allan Detsky, "although many patients prefer not to 'know' or 'try' [when death is near], the majority of those who seek health care prefer active strategies…. an extra test or two, 'just to be sure,' is often preferred to possibly missing something."[57] These impulses are furthered by family members, who may fear the feeling that they "didn't do enough" to help their ill loved one and therefore encourage further treatment.

The culture of intervention at end of life is also supported by medical and legal policies in the healthcare system more generally that incentivize "defensive medicine."[58] Defensive medicine – doing more than what is necessary for the patient in order to protect the physician – is driven by physicians' fears of malpractice, which is substantial: in 2008, malpractice costs were estimated at $55 billion per year, accounting for approximately 2.5% of annual overall health care spending.[59] The fee-for-service reimbursement model further promotes defensive medicine as it incentivizes providers for the number of tests and procedures they order. While the development of new technologies has brought promise to patients and their providers, advances "create opportunities for error in diagnosis and treatment," as studies have shown that liability claims increase when new technologies are introduced (though level off over time).[60] The technologies that patients put their hopes in further drive the costs of their care, though the question remains the extent to which they improve their outcomes. Indeed, studies show that of the many advances which seek to improve care, physician's open and honest

[57] Detsky, "What Patients Really Want from Healthcare," 2500.
[58] Carroll, "To Be Sued Less, Doctors Should Consider Talking to Patients More."
[59] Carroll, "To Be Sued Less, Doctors Should Consider Talking to Patients More."; Mellow et al., "National Costs of the Medical Liability System."
[60] Jacobson, "Medical Liability and The Culture of Technology."

communication with their patients does the most to satisfy patients and decrease the chance of malpractice suits.[61]

For end-of-life care specifically, the pressure to treat has been furthered even more by legal decisions that have sought to protect the critically ill from negligent treatment. The "Baby Doe" regulations of the mid-1980s required treatment of potentially handicapped infants, while an amendment to the Child Abuse and Protection Act of 1984 broadened the scope of what counts as "medical neglect" to include the withholding of medically indicated treatment for infants with life-threating conditions.[62] Though targeted at pediatrics and the protection of medically fragile children, these kinds of decisions have drawn a connection between withdrawal of care and neglect or mistreatment. They communicate to the broader care community that more than fewer interventions is the right path.

[61] Carroll, "To Be Sued Less, Doctors Should Consider Talking to Patients More."
[62] Himelstein, Hilden, Boldt, and Weissman, "Pediatric Palliative Care," 1759.

II. INFRASTRUCTURE

Medicare and Hospice

Since the first hospice opened in 1973, the care we provide those near the end of life has come a long way. While deep resistance and discomfort remains, for the individuals who face it as well as the providers who face the limits of what they can do to help, we are far from that "death-denying society" that Kubler-Ross identified. The integration of end-of-life care has been profoundly furthered by policies designed to support it, the primary being the Medicare Hospice Benefit (MHB), which was established in 1983 to provide reimbursement for hospice services. Together with quality measurement, which seeks to ensure accountability for the services reimbursed, the MHB is a central support for end-of-life care and has given access to care for countless individuals in need.[63] It is an essential benefit, but also flawed. Considering the extent to which reimbursement shapes care delivery, and the growing population of beneficiaries who will need it, analysis of its shortcomings is crucial to support its improvement and ensure that it meets the needs of its beneficiaries.

[63] While this report discusses palliative care, it focuses on hospice as palliative care is not currently covered under the Medicare Hospice Benefit or evaluated by the HIS and CAHPS quality measurements which will be examined.

A GROWING INDUSTRY

In 2015, Medicare spent over $615 billion on its beneficiaries' care, 25% of which on their last year of life, and of that, over 75% on the last month.[64] This trend speaks to the high utilization of interventional care at end of life, which is only expected to rise as the coming "silver tsunami" of the country's aging population brings longer lifespans, as well as higher, continued care costs.[65] Indeed, 9 out of 10 Medicare beneficiaries have one or more chronic conditions (including cancer, organ system failure, dementia or stroke), and the incidence of cancer is expected to rise 45% in the next twenty years.[66] Though people are living longer lives, they are not necessarily healthier ones, and the costs of their care – particularly at end of life – are profound (estimated to reach $346 billion by 2040).[67] Reflecting this growth, Medicare expenditures on hospice increased from $2.9 billion in 2000 to over $18 billion today, while the number of hospices in operation has grown from 10 at the time of the MHB's founding, to over 5,800 by 2013.[68]

---

[64] Nakhoda, "End-of-life Care and the Medicare Hospice Benefit," 25.; Gozalo et al., "Changes in Medicare Costs With The Growth of Hospice Care in Nursing Homes," 1824.; Edens, Harvey and Gilden, "Developing and Financing a Palliative Care Program," 380.
[65] Nakhoda, "End-of-life Care and the Medicare Hospice Benefit," 24.; Hartjes, "Making the Case for Palliative Care," 291.
[66] Ibid.
[67] Hartjes, "Making the Case for Palliative Care," 291.
[68] Thompson, Carlson and Bradley, "US Hospice Industry," 1287.; Stevenson, "Growing Pains for the Medicare Hospice Benefit," 1684.; "Hospice Care in America."

THE MEDICARE HOSPICE BENEFIT

The creation of the MHB in 1983 made it possible for those near the end of their lives to access crucial support by providing reimbursement for hospice services and effectively expanding the number of providers in operation. However, the MHB has largely remained unchanged since its founding, and in recent years has come under criticism for its structure which, despite the benefits, has restricted access for many patients and incentivized the wrong kind of care by providers. The primary criticisms of the MHB stem from its eligibility requirements for patients. In order to be eligible the patient must: 1) be eligible for Part A (hospital services), 2) have a prognosis of six months or less to live, 3) sign a statement forgoing all curative treatment under their usual Part A coverage, and 4) receive hospice from a Medicare approved provider.[69] The requirement for a six-month prognosis and the forgoing of curative treatment, in particular, are cited as the major reasons why individuals enter hospice care late.[70]

First, the requirement for a six-month prognosis fails to appreciate the changing demographics of those in need of hospice. While cancer has historically been the primary diagnosis, today there are many in need of hospice with diseases such as heart disease, Alzheimer's, or pulmonary failure that are terminal but do not follow as clear a disease trajectory.[71] The inaccuracy of prognoses for these diseases is often made worse by

---

[69] Jennings, Ryndes, D'Onofrio, and Baily, *The Hastings Center,* 27.; Nakhoda, "End-of-life Care and the Medicare Hospice Benefit," 24.
[70] Nakhoda, "End-of-life Care and the Medicare Hospice Benefit," 26.
[71] Jennings, Ryndes, D'Onofrio, and Baily, *The Hastings Center,* 28.

overestimation by physicians, rooted in their lack of training with end-of-life discussions and their own unwillingness to begin such conversations when the efficacy of curative interventions begins to decline.[72] As found in the study by Rady and Johnson, "when physicians' estimates of life expectancy were based solely on disease severity, survival probabilities were commonly overestimated and misled patients when asked about preferences for the appropriate care in certain chronic diseases." [73]

Second, the requirement that patients forgo curative treatment likewise fails to appreciate the individual needs of patients and their specific disease trajectory. The requirement, intended to keep patients from 'double dipping' in their Part A benefits, in effect reinforces the idea of end-of-life care as "giving up."[74] It creates a false choice between curing a disease (life) and withdrawing care (death), and fails to appreciate the spectrum of medical interventions and palliative treatments available to patients. Concurrent care, on the other hand, allows the patient to receive "curative care to eradicate disease or normalize the underlying health condition, while simultaneously receiving hospice care for physical symptoms and psychosocial needs at end of life."[75] Despite the substantial body of evidence that proves the benefits of hospice care, this provision in most cases pushes patients to choose continued interventions, despite the delay it ultimately causes in accessing hospice's more supportive therapies.[76]

---

[72] Rady and Johnson, "Admission to Intensive Care Unit," 710.
[73] Ibid, 709.
[74] Kang et al., "Integration of Palliative Care," 320.
[75] Lindley, "Health Care Reform," 81.
[76] Ibid, 82.

For providers, the MHB is also flawed. The MHB reimburses on a flat, per diem rate according to four payment categories: routine home care (RHC); continuous home care (CHC); general inpatient care (GIC); and inpatient respite care (IRC).[77] Each are paid at different rates, which are set on a regional basis, adjusted for the specific costs of care (e.g. labor), and increased according to increases in the prices for the hospital market basket (described as a "fixed-weight index").[78] The vast majority of hospice claims (96%) are submitted for RHC: in 2008 the rate was $135.11, by 2015 it had increased to $159.[79]

Several issues with the per diem payment structure have been well documented. First and foremost, the per diem rate is paid to hospice providers for each day of the patient's enrollment, regardless of the level of care required or its costs. A study by Huskamp et al. on hospice cost variation found that the largest driver of cost is the length of stay, with care costs highest at the beginning (when staff is getting acquainted with the patient's needs), and at the end (as more intensive palliative care is required at time of death).[80] No matter the variation, providers are paid the same amount for each day of care. The per diem rate also fails to take into account the costs of palliative interventions, which are often very high. For example, palliative chemotherapy – primarily used for

[77] Huskamp et al., "Variation in Patients' Hospice Costs," 234.
[78] Von Gunten, "Financing Palliative Care," 775.; Huskamp et al., "Variation in Patients' Hospice Costs," 234.
[79] Gozalo et al., "Changes in Medicare Costs With The Growth of Hospice Care in Nursing Homes," 1830.; Huskamp et al., "Variation in Patients' Hospice Costs," 234.
[80] Huskamp et al., "Variation in Patients' Hospice Costs," 241.

symptom reduction – is estimated at $30,000 per treatment.[81] At $159 per day, the MHB's reimbursement goes little of the way to cover these costs, and instead has the effect of incentivizing providers to avoid higher cost patients.[82]

Despite its poor reimbursement, the MHB remains the lifeblood of the hospice industry: 75% of reimbursement for hospice services comes from the MHB, while 12% comes from private insurance and 7% from Medicaid and donations.[83] Hospice providers, therefore, must find ways to make ends meet largely with what little the MHB provides. Unlike their non-profit counterparts who also receive support from foundations and grants, for-profit providers operate on razor thin margins. Research has identified distorted enrollment patterns between for-profit and non-profit providers, as for-profits more frequently target patients whose prognoses are more uncertain and will likely result in a longer length of stay.[84] Patients with lower day-to-day care needs, but longer overall anticipated lengths of stay, represent the "best" way for providers to recoup their costs.[85]

This trend speaks to a central inconsistency of the MHB: while it penalizes providers for keeping patients past their prognoses, the low per diem payment incentives longer lengths of stay as hospice providers need to balance the costs of providing care to

---

[81] American Society of Clinical Oncology, "The Debate in Hospice Care," 155.
[82] Nakhoda, "End-of-life Care and the Medicare Hospice Benefit," 26.
[83] Jennings, Ryndes, D'Onofrio, and Baily, *The Hastings Center,* 27.; Nakhoda, "End-of-life Care and the Medicare Hospice Benefit," 24.
[84] Thompson, Carlson and Bradley, "US Hospice Industry," 1287.
[85] Whoriskey and Keating, "Dying and Profits."

those who enter hospice late and require acute care.[86] The reimbursement structure is based on the logical assumption that hospice is for people at the very end of life and they die as presumed by their prognosis (as if they do not, then they should not be on hospice). However, this is often inconsistent with the reality of the provider where the schedule of payments often does not match the patients' actual disease trajectories, or their costs.[87]

In addition to selective enrollment, research also found that for-profits offer a more narrow range of services: they are less likely to offer palliative radiation (an effective, though costly, tool for symptom management) as well as bereavement and family support services, and have lower proportions of higher qualified staff (e.g. registered nurses or social workers).[88] Though in pursuit of the care needs of the exploding population of elders, for-profits struggle to operate on low reimbursement and the downward pressure to cut costs is ultimately shouldered by patients.[89]

While disagreement exists in the research community as to the exact reasons for differences between for- and non-profit providers, there have been a sufficient number of studies pointing to the disproportionate growth of for-profit hospices (and subsequent

---

[86] Delayed enrollment is the byproduct of lack of awareness and cultural resistance to considering alternatives to intervention: 50% of patients spend less than 19 days in hospice and 35% less than seven days. American Medical Association, "Average Hospice Length of Stay is Falling."

[87] Passik et al., "Is There a Model for Demonstrating a Beneficial Financial Impact," 420.; Gozalo et al., "Changes in Medicare Costs With The Growth of Hospice Care in Nursing Homes," 1829.; Obermeyer, et al., "Association Between the Medicare Hospice Benefit and Health Care Utilization," 1893.; Thompson, Carlson and Bradley, "US Hospice Industry," 1286.

[88] Thompson, Carlson and Bradley, "US Hospice Industry," 1287.; Stevenson, "Growing Pains for the Medicare Hospice Benefit," 1684.

[89] Between 2000 and 2009, of the 1,710 new hospices that opened, over 80% were for-profit, compared to 1999 when 62% of hospices were non-profit. Thompson, Carlson and Bradley, "US Hospice Industry," 1288.

inquiries into their enrollment practices and quality of care) to inspire the Medicare Payment Advisory Commission (MedPAC) to reexamine the MHB with an eye towards how it influences the demographics of hospice providers and the care they provide.[90]

THE BEGINNING OF REFORM

Under the leadership of MedPAC, researchers, advocates, and policymakers have begun analyzing the full extent of the MHB's influences on end-of-life care. As a first step, MedPAC, along with the HHS Office of Inspector General, highlighted the potential for hospice providers to use selective enrollment as a means to maximize financial gain, going so far as to say that the MHB may in effect "distort patterns of enrollment and use."[91] Given their findings that the incentives are misaligned with quality care and timely enrollment, improvement should "try to project backward both to improve the local health care system's ability to deliver seamless and better care, as well as to introduce hospice care earlier so as to potentially enjoy the benefit of greater numbers of people admitted to and followed in hospice for longer than 30 days."[92] This would allow providers to have a greater number of patients whose care is less short, acute, and costly, so that other patients do not have to carry the disproportionate weight of their care.

---

[90] Thompson, Carlson and Bradley, "US Hospice Industry," 1291.
[91] Gozalo et al., "Changes in Medicare Costs With The Growth of Hospice Care in Nursing Homes," 1824.; Thompson, Carlson and Bradley, "US Hospice Industry," 1286.
[92] Passik et al., "Is There a Model for Demonstrating a Beneficial Financial Impact," 420.; Stevenson and Huskamp, "Hospice Payment Reforms."

Consistent with this goal, CMS introduced its own solution. In 2015 it issued a hospice payment rule for fiscal year 2016, "the first significant changes to hospice payment methodology since the Medicare benefit went into effect in 1983."[93] While the core eligibility requirements remain unchanged, the proposed revisions significantly alter the payment mechanism by creating "service intensity add-on" (SIA) payments, which provide higher reimbursement at the beginning and end of an enrollee's care for face-to-face services provided by a registered nurse or social worker. These payments better reflect the reality of providing hospice care, including the periods of higher intensity and cost. SIA payments will be made on top of the usual per diem rate and can be charged up to four hours per day.[94] SIA payments in effect make longer lengths of stay no longer as necessary, and shorter lengths of stay no longer as disproportionately costly. In addition to the SIA, CMS' rule created differential payment of two separate rates for routine home care: care for days one through sixty, and care for days sixty and after, again reflecting that care needs are not uniform throughout an enrollee's hospice stay.[95]

Another critical element of CMS' rule is the authorization of payment for doctors' consultations with patients about end-of-life care options (advance care planning). Originally waylaid by Sarah Palin's "death panels" controversy and the general toxicity surrounding health care reform, advance care planning regained ground with legislative support in both the Senate (the Care Planning Act of 2015) and House (Personalize Your

[93] Stevenson and Huskamp, "Hospice Payment Reforms."
[94] Stevenson and Huskamp, "Hospice Payment Reforms."; "Key Legislation Affecting Home Care and Hospice."
[95] "Key Legislation Affecting Home Care and Hospice."

Care Act of 2013).[96] The CMS rule will help individuals learn about their care options, determine which best fit their wishes, and share those wishes with family, friends, and care providers. For these consultations, Medicare will pay $86 for the first 30 minutes of the session in a doctor's office, $80 in a hospital, and $75 for every additional 30 minutes. The new billing codes will be in the physician fee schedule, and the consultation happens "at the discretion of the beneficiary" – at their specific request – to allay fears of bureaucrats forcing unwanted discussions or choices.[97]

Despite these important first steps at reform, CMS' failure to revise the eligibility requirements for patients to receive hospice remains a substantial hurdle. However, early experimentation with revised eligibility is under way. In 2016, the Medicare Care Choice Model begins: a three-year, budget neutral demonstration project made possible under the ACA to assess if patients who remain eligible for both curative and hospice interventions experience improved quality of care, satisfaction, and effectiveness of medical interventions. The program will be piloted in 140 hospices for hospice-eligible patients. Hospice providers will be reimbursed on a monthly rate, between $200 and $400, which will be phased in over the next two years. The program is expected to reach at least 150,000 eligible Medicare patients.[98]

This model builds off the ACA's provision on concurrent care for children, which requires state Medicaid/CHP programs to allow children under the age of 21 with a six-

[96] "10 FAQs: Medicare's Role in End-of-Life Care."
[97] Pear, "New Medicare Rule Authorizes 'End-of-Life' Consultations."; "10 FAQs: Medicare's Role in End-of-Life Care."
[98] Stevenson and Huskamp, "Hospice Payment Reforms."; "Medicare Care Choices Model."

month prognosis to receive hospice and curative care simultaneously.[99] While neither the Medicare Care Choice Model nor the children's program on which it is based revise the six-month prognosis requirement, early findings show that concurrent care is, indeed, a positive change. Reported benefits of concurrent care for children include: improved patient-physician communication, easier transitions between care providers, improved patient and family satisfaction, and decreased financial burden on families.[100] These findings encourage support for concurrent care and its expanded provision to adults.

[99] Kang et al., "Integration of Palliative Care," 321.
[100] Lindley, "Health Care Reform," 84.

Quality Measurement

End-of-life care developed from a foundation of religious and ethical obligations to the critically ill and dying. The MHB represented the United States' acceptance of end-of-life care as a worthwhile modality, and despite its shortcomings, it has continued to provide access to care for many beneficiaries. Recent reforms have continued this commitment through efforts to improve and expand end-of-life care services. Fulfilling this promise, however, requires the mechanisms for assuring quality. Quality measurement is critical for this process.

In the ACA environment, which seeks to replace fee-for-service with pay-for-performance, quality measurement is closely tied to reimbursement and as such, is an essential piece of the structure that supports end-of-life care. Measurement of end-of-life care is complicated, however, by the very individual nature of death itself. Research on what patients and their families want at end of life often centers on this question of what makes "a good death," and research findings critically inform the measures used to judge its success. With consideration of the holistic, person-centered model that is hospice care, it is all the more important to ensure quality measurement reflects what patients, not politics, want at end of life, to ensure the care provided – and reimbursed – is the care patients and their families want and need.

"A Good Death"

Trying to define what makes a "good death" is a difficult, if not impossible, task, as death and dying mean very different things to different people and are impacted by cultural, social, and religious norms. As much as we want, "we cannot suppress the question of what counts as a 'good death' (or perhaps more accurately, 'dying well') and what counts as good care near the end of life.[101] Categories of care provide ways to organize the range of patient preferences collected in research, and reflect the different dimensions of holistic care. The first category – *physical* – captures the importance of having a safe and clean environment in which to be ill and ultimately die, sufficient food and nutrition, good pain control and symptom management, and attention to personal care. The *emotional* category highlights the preservation of dignity and self-worth, respect for patient wishes, information on emotional changes and the availability of counseling, advance planning and spiritual guidance. The *social* category highlights the importance of companionship, narration of life, resolving relationships, and settling unfinished business.[102]

Research on experiences at end of life reveals trends within each of the three categories, which together can suggest a common understanding of what makes "a good death." Within the category of emotion, fear predominates. Patients frequently report fears about losing control – both physically (succumbing to the disease) as well as cognitively (no longer being mentally aware or in a position to make decisions about one's care). Also common is the fear of loss of independence and dignity, a fear that the

[101] Jennings, Ryndes, D'Onofrio, and Baily, *The Hastings Center,* 6.
[102] Ibid.

force of their illness will subsume them, along with their wishes.[103] There is also great fear reported within the physical category: about not knowing what is going to happen to them, or how much pain they will suffer in the process of dying. There are also commonly reported fears of being a burden; conversely, the fear of being abandoned is also frequently cited.[104]

It is no surprise that when contemplating death, one is fearful. But what is clear from patient report is that in dying there are also opportunities to reflect and gain self-awareness that many fail to take advantage of while in good health. Within the social category of care these include making meaning of the life lived and gaining a sense of "completion."[105] For many suffering from a terminal illness, the trajectory of their disease signifies that at some point they will be unable to articulate their own wishes. A common desire, therefore, is that the individual finds ways to remain autonomous. Ensuring preferences are respected and receiving empathic care are two common goals expressed by dying patients.[106] These findings emphasize the importance of advance care planning so that individuals' wishes are respected even when they can no longer articulate them; unfortunately, while 80% of people said they would want to talk with their doctor about plans for end of life, only 7% actually do.[107]

---

[103] Jennings, Ryndes, D'Onofrio, and Baily, *The Hastings Center,* 13; Steinhauser et al., "Factors Considered Important," 2481.; Nakhoda, "End-of-life Care and the Medicare Hospice Benefit," 24.
[104] Steinhauser et al., "Factors Considered Important," 2481.; Nakhoda, "End-of-life Care and the Medicare Hospice Benefit," 24.
[105] Ibid.
[106] Ibid.
[107] Wessman, Sona and Schallom, "Improving Caregivers' Perceptions," 2.; Hartjes, "Making the Case for Palliative Care," 292.

Despite Sarah Palin's toxic mythmaking, end-of-life counseling is a deeply patient-centered service: enabling patients to be the directors of their own care, whether it be to continue aggressive interventions or withdraw care and focus on comfort and support. Studies show that when asked, more often than not patients voice their desire to stop treatments and focus instead on quality of life for the time remaining. One study found that patients who had end-of-life conversations had 36% lower expenses from decreased interventions, suggesting that when given the chance to discuss alternatives, many patients choose to forgo further intervention.[108]

There are many community-based programs that provide advance care planning and support that speak directly to patient preferences, with positive results. In his study of a California program called Advanced Illness Management (AIM), which is modeled off of the Respecting Choices model, an evidence-based advanced care planning model, Harris Meyer identified significant barriers to entry to hospice such as fear. By providing warm hand-offs between providers, AIM proved effective in supporting communication around wishes for care and decreasing patients' fears about hospice – not as a place to die, but as a means to live with quality.[109] Through symptom management, care planning, and psychosocial support, AIM uses a patient-centered approach that responds to the voices of its patients.[110] AIM also proves financially beneficial: among its client population, there was a reduction in hospitalizations and inpatient direct care costs on

[108] Nakhoda, "End-of-life Care and the Medicare Hospice Benefit," 25.
[109] Harris, "Changing the Conversation," 392.
[110] Ibid.

average of $2000 per month.[111] While health care savings are valuable data to build support for this model of care, more important is how AIM shows that end-of-life conversations do not force individuals into decisions against their will, but rather opens communication about end of life and the options for care available. In the words of AIM's project manager, "we're just doing what people ask. We are most explicitly not pulling the plug on Granny."[112]

QUALITY UNDER THE ACA

Research has shown that end-of-life care increases patient satisfaction, improves outcomes, and does so at decreased cost. It is, in many ways, an exemplar of the Institute for Healthcare's "Triple Aim," the "broader system of linked goals" of improved patient experience, population health, and decreased cost that are the main framework for the ACA.[113] To achieve this vision, with awareness that "our [current] healthcare system is unaffordable and fails to deliver consistent quality," policy has refocused its efforts on quality reporting with the understanding that "we need good measures of quality healthcare so we can direct our limited resources where they provide the most value."[114] To do this for hospice, the ACA created the Hospice Quality Reporting Program (HQRP), whose measures and the processes by which they are reported are determined

[111] Harris, "Changing the Conversation," 393.
[112] Ibid.
[113] Berwick, Nolan and Whittington, "The Triple Aim," 760.
[114] Rotella, "The Devil is in the Denominator."

by CMS.[115] The ACA also gave CMS the ability to change the hospice payment methods, though required that they be budget neutral. While cost is often the primary policy metric for success, "the ultimate verdict concerning hospice's integration into the broader health care system will be determined by the quality of end-of-life care that patients receive."[116]

CMS ultimately developed two sets of data which hospices are required to submit: the Hospice Item Set (HIS) and the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice survey. Informed by the ACA's "pay-for-performance" model of quality assurance, hospices are penalized by 2% in the next fiscal year for each year that they do not submit the required data.[117] It bears noting, however, that the requirement currently is only "'pay-for-reporting,' meaning it is the act of submitting the data that determines compliance," and not the quality of performance.[118] While a performance-oriented penalty would presumably affect quality, some believe the current compliance test represents an "easing in" of quality reporting requirements for both the industry and CMS. It provides CMS data for developing future performance-based penalties, and allows hospice providers time to prepare for closer examination of their services.[119]

Additionally, while CMS is required to establish procedures to make the reported data available to the public, as well as give hospice providers time to review data before

---

[115] "Quality Reporting."; Webb and Kamal, "Integrating the Biopsychosocial Model," 1.
[116] Stevenson, "Growing Pains for the Medicare Hospice Benefit," 1685.
[117] "Quality Reporting."
[118] Ibid.
[119] Meyer, J., personal communication, March 24, 2016.

its dissemination, it has not set a date for public availability of the reported data.[120] The reputational effects of having data shared with the public could lead some hospice providers to improve their services, a different kind of incentive in the absence of CMS' penalties for poor performance. To that end, studies have found "strong evidence of the effectiveness of public reporting on quality improvement," as "public reporting is thought to be a key strategy for influencing market forces and, to a lesser extent, professionalism."[121] However, as currently no data is disclosed, it is impossible to evaluate the reputational effects sharing would achieve.

In pursuit of clarity on CMS' intent for its hospice reporting requirements, this author submitted an inquiry to CMS on the intent of pay-for-reporting and the reason for withholding the data from the public. CMS responded that it has determined that four quarters of data is needed to validate the data before releasing it to the public. CMS writes:

> CMS recognizes that it is essential that the data made available to the public be meaningful and that comparing performance between hospices requires that measures be constructed from data collected in a standardized and uniform manner. It is also critical to establish the reliability and validity of the measures prior to public reporting in order to demonstrate the ability of the measures to distinguish between the quality services provided. To establish reliability and validity of the quality measures, at least four quarters of data will need to be analyzed. In addition, the Affordable Care Act requires that reporting be made public on the CMS Website. Providers will have an opportunity to review their quality data prior to public reporting.[122]

---

[120] "Quality Reporting."
[121] Hibbard, Stockard, and Tusler, "Hospital Performance Reports," 1150.
[122] Centers for Medicare and Medicaid Services, email communication, April 11, 2016.

This response speaks both to the presumed "easing in" of reporting requirements as well as the delay in releasing collected data to the public. While it remains unclear to this author from CMS' response whether it intends to shift from pay-for-reporting to pay-for-performance after the four quarters conclude, this first step by CMS to ensure that its measures are validated and allow for accurate comparison is important, and will ultimately allow patients to be more informed consumers of their healthcare.

Quality measurement has little effect if its findings are not used to hold those measured accountable, and the current penalties, though short of pay-for-performance, acknowledge that incentives are necessary to spur change. As Berwick, Nolan and Whittington write in *Health Affairs*, the pursuit of the Triple Aim "is not congruent with the current business models of any but a tiny number of US healthcare organizations."[123] They continue: "from the viewpoint of individual actors responding to current market forces, pursuing the three aims at once is not in their immediate self-interest… The great task in policy is not to claim that stakeholders are acting irrationally, but rather to change what is rational for them to do."[124] This echoes the Institute of Medicine's call in its report *Dying in America* that, "federal and regulatory action [is needed] to establish financial incentives for integrating medical and social services for people nearing the end of life."[125] When taken together with the introduction of SIA payments to better support

[123] Berwick, Nolan and Whittington, "The Triple Aim," 760.
[124] Ibid, 761.
[125] "10 FAQs: Medicare's Role in End-of-Life Care."

providers in their care of high needs patients, the penalization (albeit weakly) attempts to provide an additional financial incentive to improve behavior.

HIS, CAHPS, AND PATIENT PREFERENCE

The Hospice Item Set (HIS) is one of two surveys used by CMS for quality measurement of hospice services. The HIS collects patient-level data at time of admission (within 14 days) and at discharge or end of care (within 7 days). Unlike surveys that are given to patients or their caregivers, the HIS is formed from data taken from the patient's medical record and is therefore more standardized.[126] The data drawn from the medical records is used to calculate scores along seven different domains [see Appendix A for specific measures], endorsed by the National Quality Forum (NQF):

1. NQF #1617: Patients Treated with an Opioid who are Given a Bowel Regimen
2. NQF #1634: Pain Screening
3. NQF #1637: Pain Assessment
4. NQF #1638: Dyspnea Treatment
5. NQF #1639: Dyspnea Screening
6. NQF #1641: Treatment Preferences
7. Modified NQF #1647: Beliefs/Values Addressed (if desired by the patient)[127]

The measures used in the HIS represent "the largest evolution in hospice quality monitoring," as previous item sets were far more limited – e.g. one process and one structural measure – and were formed from the fourteen quality measures that NQF endorsed in 2012.[128] [Appendix B] The HIS focuses on primary medical symptoms like

[126] "Hospice Item Set."
[127] "Hospice Item Set."; Webb and Kamal, "Integrating the Biopsychosocial Model," 1.
[128] Webb and Kamal, "Integrating the Biopsychosocial Model," 1.

pain and dyspnea, or shortness of breath, with attention paid to the ethical/legal elements of care related to patient decision making and beliefs.

The Consumer Assessment of Healthcare Providers and Systems (CAHPS) hospice survey is given post-death to the patient's caregiver to assess the patient and family experience. The purpose of this survey is: 1) to provide public information about providers to assist future patients in the selection of their provider, 2) to help providers with their own quality improvement initiatives, and 3) to provide CMS with data on providers for their monitoring and evaluation.[129] Administered by mail, telephone, and mail with telephone follow-up, the survey is required only for hospices with over fifty patients, and data is required quarterly. The CAHPS hospice survey consists of eleven quality measures, consisting of composite, single item, and global measures, the combination of which "allows consumers to quickly review the caregiver's experience with hospice care."[130] [Appendix C]

Comparing these measurement tools against the categories of patient experience desired at end of life reveals the extent to which CMS' requirements ultimately support the provision of care patients desire. As previously stated, research on patient preference has highlighted common desires including: the maintenance of physical comfort (e.g. being kept clean, out of pain), the concern for caregivers and family (e.g. the burden of care, their own preparation for the patient's death, resolving conflicts), the maintenance of dignity and accomplishing a sense of peace (e.g. their own sense of completion, having

[129] "CAHPS Hospice Survey Fact Sheet."
[130] Ibid.

someone to talk to about their fears and reflections), and desires regarding place and kind of death (e.g. having certain people present, comforts like specific food, music, or environment).[131] [Appendix D]

Examining the measures that the HIS and CAHPS collect show that patient wishes are, generally, well represented in CMS' evaluation, both in regards to individual items as well as the broader categories of care. Within the emotional and physical categories, both the HIS and CAHPS capture important dimensions of quality end-of-life care as identified in research on patient preferences. In the category of *physical*, which focuses on the importance of a clean and safe environment, good personal care, and comprehensive symptom management, the HIS assesses for "getting help for symptoms," "understanding the side effects of pain medication," and "getting timely care."[132] The CAHPS similarly assesses for "pain screening and assessment" and "dyspnea screening and treatment."[133] In the category of *emotional*, both surveys capture the value of dignity and self-worth, respect for patient wishes, timely information provided to patient and family for planning purposes, as well as spiritual guidance and counseling. The HIS in particular assesses for many dimensions within this category: "hospice team communication," "treating family members with respect," "providing emotional support," "support for religious and spiritual beliefs," and "information continuity."[134]

---

[131] Matsuyama, Reddy and Smith, "Why Do Patients Choose Chemotherapy," 3490.
[132] "Hospice Item Set."
[133] "CAHPS Hospice Survey Fact Sheet."
[134] "Hospice Item Set."

The CAHPS, while more focused on clinical symptoms (the physical category), also assesses "treatment preferences" and "whether beliefs/values were addressed."[135]

Despite their attention to the physical and emotional categories of care, both measures lack attention to the *social* category, which attends to the importance of companionship, the desire to narrate one's life (remembering one's accomplishments and reflecting on them to find completion), and resolving conflicts and unfinished business. These desires are as important as managing symptoms, as without their resolution they can contribute to angst and anxiety that contribute to a poorer overall experience.[136] For example, advance care planning materials exist that give individuals the space not only to articulate their desires for care, but also to explore issues such as unresolved conflicts. "Five Wishes" is an easy-to-read advance directive published by Aging with Dignity, which includes space to write about unresolved conflicts, leave messages for those with whom they have lost touch, or reflect on their own lives. While opportunities for these reflections are more expansive in the adolescent version, "Voicing My Choices," both provide more space than standard advance directives to explore these components of one's social needs and speak to the importance of providing a space to do so.[137]

Despite the fact that standard end-of-life assessments include screening for depression and anxiety, psychological stressors are most poorly represented on both HIS and CAHPS measures. While the CAHPS survey collects information on the level of

[135] "CAHPS Hospice Survey Fact Sheet."
[136] Webb and Kamal, "Integrating the Biopsychosocial Model," 1.
[137] Ibid.

emotional support received and the extent to which concerns were listened to and addressed, only one question specifically identifies psychological symptoms of anxiety or sadness.[138] This disparity is even more severe with the HIS. As Webb and Kamal write in their editorial, the HIS excludes psychological measures "despite the recommendations of the American College of Physicians clinical practice guidelines for regular assessment of this common symptom in palliative care and at the end of life," which is significant as medical symptoms can be worsened by unmet psychological needs.[139] The HIS in particular makes clear distinctions among physical, emotional and psychological symptoms, despite robust research – and the model of hospice care itself – that argues for their interconnectedness.

As the study by Schenck et al. on measures of hospice and palliative care confirmed, there is disproportionate focus in measurement on physical domains of care to the detriment of other domains. They found that out of 174 measures analyzed, 47% were focused on physical symptoms, followed by "structure and process."[140] It bears further exploration, therefore, on how to better incorporate the psychosocial dimensions of end-of-life care into hospice quality measurement, so that CMS reimbursement supports the provision of care that truly meets the whole spectrum of a dying patient's needs.

---

[138] "CAHPS Hospice Survey Fact Sheet."
[139] Webb and Kamal, "Integrating the Biopsychosocial Model," 1.; Campbell, Clauw and Keefe, "Persistent Pain and Depression," 403.
[140] Schneck et al., "The PEACE Project," 1454.

Recommendations

The Medicare Hospice Benefit and the Hospice Quality Reporting Program are two critical supports upholding hospice: the mechanism that pays for services, opening access to individuals in need and supporting providers who seek to serve them, and measuring quality to capture clinical outcomes of individuals and assess the performance their providers. Both reflect honest, earnest desires to expand access and ensure quality at end of life, but as has been explored, both have substantial shortcomings that limit their ultimate effectiveness. From the belief that only by identifying what is flawed will we be able to improve, the following are recommendations on how to strengthen these pillars of the hospice infrastructure.

MEDICARE HOSPICE BENEFIT

Despite its many benefits, the criteria eligibility for the MHB ultimately delays entry into hospice for many patients. The primary recommendation, therefore, is to remove unnecessary barriers that delay entry into hospice so that the benefits to patients – as well as the substantial cost savings – can be more fully realized. This can be accomplished by revising the six-month prognosis requirement, reimbursing for concurrent care, and promoting palliative care programs in hospitals and outpatient care centers.

First, expanding the six-month prognosis requirement to more closely reflect the disease demographics of those in need of hospice would expand access for many patients and promote their timelier enrollment. As has been reviewed, the benefits of hospice are substantial both to the individual and their families, as well as in terms of cost savings. Restricting individuals whose disease trajectory is more protracted to the six-month timeline ensures that by the time they reach the final months of their life, they will have missed many of the opportunities that hospice provides, and their benefits, too, will not be as clearly felt. This is particularly true for the growing population of patients with degenerative brain disorders such as Alzheimer's, whose disease course can be prolonged.

Second, the promotion of concurrent care would effectively bring end-of-life care further upstream in the care continuum and also promote timelier enrollment. As early research shows, and as has already been proven on the pediatric level, concurrent care improves outcomes as well as decreases costs. The longer a patient is enrolled in hospice, the better their outcomes and the greater their savings.[141] While resistance to concurrent care stems from the feared costs of beneficiaries "double dipping" in their Part A benefits, timely enrollment actually decreases the number of ICU visits and other aggressive interventions that are significant drivers of healthcare spending at end of life.

Third, the promotion of palliative care programs in hospital and outpatient care settings would help introduce patients, families, and their providers earlier to end-of-life

[141] Ogundimu, "Concurrent Care: the Buzzword in Hospice Services."

care. As palliative care is often introduced to patients closer to diagnosis, it can provide the means of giving the warm handoff between providers and facilitate the transition to hospice (if that is the patient's wish). As California's AIM program showed, warm handoffs help ease the fears surrounding care transitions, and ensure that through supportive communication and assistance with advance care planning, patients' goals for quality of life are paramount.

HOSPICE QUALITY REPORTING PROGRAM

The HIS and CAHPS surveys offer comprehensive assessments of hospice experience; however, as with the MHB, there remain opportunities for improvement. First and foremost, social and psychological measures should be better represented in both, considering the centrality of psychosocial experiences to clinical outcomes. As a review of both surveys found that they disproportionately focus on physical symptoms, it is imperative that they incorporate measures more reflective of hospice's holistic model of care and in particular, the specific domains voiced by patients as those most important to them. Otherwise, measurement assesses for services and outcomes that may not reflect patient preferences, ultimately sustaining a provision of hospice that does not meet their needs. And though quality measurement is not *yet* used for performance-based penalties, when it is used it will be all the more important that it reflects patient preference, so that providers are rewarded for giving the kind of care patients want.

As an example of how measurement can more accurately reflect holistic care, in 2013 the National Consensus Project for Quality Palliative Care updated its clinical practice guidelines for palliative care, in acknowledgement of the importance of incorporating psychosocial factors in an assessment of care.[142] It includes: 1) structure and process of care; 2) physical aspect of care; 3) psychological and psychiatric aspects; 4) social aspects; 5) spiritual, religious, and existential aspects of care; 6) cultural aspects of care; 7) care of the patient at end of life; and 8) ethical and legal aspects.[143] Over half of its domains highlight elements of care that are not explicitly medical – e.g. the psychological, social, or existential – and could inform expanded measures in the HIS and CAHPS to capture these critical domains of experience.

As much as the measures themselves can be refined, quality measurement is meaningless if it is not used to hold providers accountable for their services. While this report found that on the whole CMS' measurements fairly represent patient preference at end of life, the failure to report that data to the public and use it for performance-based rewards and penalties deeply limits its ultimate effectiveness. As long as data is not revealed to the public, there is no potential for reputational effects to influence providers' services. And as long as data is not used, even internally, to decide on performance-based rewards and penalties, there will be no motivation to improve.

---

[142] National Consensus Project, *Clinical Practice Guidelines.*; Schneck et al., "The PEACE Project," 1451.
[143] Terry, "The New Quality Movement in Hospice," 65.

The infrastructure of hospice is too provider, not patient, centered, as it does not use measurement to hold providers accountable for their quality but is willing to limit eligibility for patients in order to control costs. Discussion in the health policy community, and CMS itself, may suggest that as the ACA develops its pay-for-performance model, the "easing in" period for hospices will end and they, too, will be subject to the same rules. But patients do not have that luxury of time, and they are the ones who deserve quality from the very beginning. Advocacy in this regard is critical; without ensuring that policy follows promise and patients truly are kept at the center of their care, its reimbursement, and its measurement, we poorly serve them in their greatest time of need.

Conclusion

The genesis of hospice care is strongly mission-driven, based in an ethical obligation to put a roof over the dying crusader's head. It is recognition that dying, in its universality, demands equitable treatment. While we are far from equity in this country, attention builds on the care we provide those at the end of life and the ways in which, by centering care around their goals, we return some semblance of control that disease has otherwise taken. Progress is evident, though at times faltering. Insurance has opened the door to hospice for Medicare beneficiaries, but restricts those who can enter it; quality measurement has sought to ensure the services provided are, in fact, quality, but does not hold providers accountable for the performance they report; and measurement captures part of the patient experience but misses much of the life of the mind.

Regardless of the distance remaining, this is progress. It encourages the integration of end-of-life care into the mainstream, and supports conversations about quality of life and care preferences in a period of life that for many of us is painful to consider. The goal is to make end-of-life care as person-centered and accountable as possible, so that it is the kind of care we would want for ourselves and our loved ones when the time comes.

Appendices

APPENDIX A: HOSPICE ITEM SET

Composite Measures

Hospice Team Communication

☐ While your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member?

☐ While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?

☐ How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?

☐ While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition?

☐ While your family member was in hospice care, how often did the hospice team listen carefully to you?

Getting Timely Care

☐ While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?

☐ How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?

Treating Family Member with Respect

☐ While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?

☐ While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?

Providing Emotional Support

☐ While your family member was in hospice care, how much emotional support did you get from the hospice team?

☐ In the weeks after your family member died, how much emotional support did you get from the hospice team?

Getting Help for Symptoms

☐ Did your family member get as much help with pain as he or she needed?

☐ How often did your family member get the help he or she needed for trouble breathing?

☐ How often did your family member get the help he or she needed for trouble with constipation?

☐ How often did your family member get the help he or she needed from the hospice team for feelings of anxiety or sadness?

Getting Hospice Care Training

☐ Did the hospice team give you the training you needed about what side effects to watch for from pain medicine?

☐ Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member?

☐ Did the hospice team give you the training you needed about how to help your family member if he or she had trouble breathing?

☐ Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?

Single Item Measures

Providing Support for Religious and Spiritual Beliefs

☐ Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?

Information Continuity

☐ While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care?

Understanding the Side Effects of Pain Medication

☐ Side effects of pain medicine include things like sleepiness. Did any member of the hospice team discuss side effects of pain medicine with you or your family member?

Global Measures

Overall Rating of Hospice

☐ Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member's hospice care?

Recommend Hospice

☐ Would you recommend this hospice to your friends and family?

APPENDIX B: NQF ENDORSED MEASURES

1634: Hospice and Palliative Care- Pain Screening (UNC) (paired with measure 1637)

1637: Hospice and Palliative Care – Pain Assessment (UNC) (paired with measure 1634)

1617: Patients treated with an Opioid who are given a bowel regimen (RAND)

1628: Patients with advanced cancer assessed for pain at outpatient visits (RAND)

1638: Hospice and Palliative Care- Dyspnea Treatment (UNC) (paired with measure 1639)

1639: Hospice and Palliative Care – Dyspnea Screening (UNC) (paired with measure 1638)

1626: Patients admitted to the ICU who have care preferences documented (RAND)

1641: Hospice and Palliative Care- Treatment Preferences (UNC)

1647: Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss (Deyta)

0209: Comfortable dying (NHPCO) (maintenance)

1625: Hospitalized patients who die an expected death with an ICD that has been deactivated (RAND)

0208: Family Evaluation of Hospice Care (NHPCO) (maintenance)

1632: CARE- Consumer Assessments and Reports of End of Life (Center for Gerontology and Health Care Research)

1623: Bereaved Family Survey (PROMISE Center)

APPENDIX C: CAHPS HOSPICE SURVEY

Composite Measures
Hospice Team Communication
Q1: While your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member? Q2: While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand? Q3: How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care? Q4: While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition? Q5: While your family member was in hospice care, how often did the hospice team listen carefully to you?
Getting Timely Care
Q1: While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it? Q2: How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?
Treating Family Member with Respect
Q1: While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect? Q2: While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?
Providing Emotional Support
Q1: While your family member was in hospice care, how much emotional support did you get from the hospice team? Q2: In the weeks after your family member died, how much emotional support did you get from the hospice team?
Getting Help For Symptoms
Q1: Did your family member get as much help with pain as he or she needed? Q2: How often did your family member get the help he or she needed for trouble breathing? Q3: How often did your family member get the help he or she needed for trouble with constipation? Q4: How often did your family member get the help he or she needed from the hospice team for feelings of anxiety or sadness?
Getting Hospice Training (In-Home Care Only)
Q1: Did the hospice team give you the training you needed about what side effects to watch for from pain medicine? Q2: Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member? Q3: Did the hospice team give you the training you needed about how to help your family member if he or she had trouble breathing? Q4: Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?
Single Items
Providing Support for Religious and Spiritual Beliefs
Q1: Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much

support for your religious and spiritual beliefs did you get from the hospice team?
Information Continuity
Q1: While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care?
Understanding Side-Effects of Pain Medication
Q1: Side effects of pain medicine include things like sleepiness. Did any member of the hospice team discuss side effects of pain medicine with you or your family member?
Global Measures
Overall Rating of Hospice
Q1: Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member's hospice care?
Recommend Hospice
Q1: Would you recommend this hospice to your friends and family?

APPENDIX D: DOMAINS OF A GOOD PALLIATIVE TREATMENT EXPERIENCE

Table 2. Domains of a Good Palliative Treatment Experience (Modified from Tong et al[41] and Steinhauser et al[42])

Domain	Definition
Physical comfort	Concerns for pain and physical symptoms
Burden on the family	Importance of relieving burdens imposed on caregiver
Location and environment	Importance of atmosphere during the experience
Presence of others	Importance of having others present during the experience
Concerns regarding prolongation of life	Desire to die naturally and in peace without the use of machines
Spiritual care	Importance of spiritual care and support
Communication	Importance of communication between the individual, the family members, and health care providers; adequate and compassionate communication about disease, prognosis, and end-of-life decisions
Completion and emotional health	Concept of completing social or emotional tasks before dying; this includes issues such as life review, resolving conflicts, spending time with family and friends, and saying goodbye
Cultural concerns	Importance of respecting cultural and religious differences and of not stereotyping minority groups; the important role of the cultural community
Individualization	Concept of respecting each death as a unique phenomenon without prescribed notions of what a good or bad death is, as well as having the ability to make individual choices concerning death; the importance of being nonjudgmental about these choices

References

Abernethy, Amy. "Culture and Financing Influence Palliative Care Services, Study Populations, and Generalizability of Research Findings." *Journal of Palliative Medicine* 11 (2008): 146.

Agency for Healthcare Research and Quality. "Closing the Quality Gap Series: Improving Health Care and Palliative Care for Advanced and Serious Illness." Last modified 2012. http://effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=1303.

Aging with Dignity. "Five Wishes." Last modified 2015. https://agingwithdignity.org/about-us.

American Medical Association. "Average Hospice Length of Stay is Falling." *AMEDNEWS*, February 1, 2012. http://www.amednews.com/article/20120201/profession/302019996/8/.

American Society of Clinical Oncology. "The Debate in Hospice Care." *Journal of Oncology Practice* 4 (2008): 153-157.

Baumrucker, S., Stolick, M., Carter, G., Lasky, T., Sheldon, J., Harrington, D., Messerschmidt, W., Oertli, K., and Morris, G. "Death, Dying, and Statistics: Quality Measures Versus Quality of Life." *American Journal of Hospice and Palliative Medicine* 27 (2010): 494-499.

Belluck, P. "Coverage for End-of-life Talks Gaining Ground." *The New York Times*, August 30, 2014. http://www.nytimes.com/2014/08/31/health/end-of-life-talks-may-finally-overcome-politics.html?_r=0.

Berwick, D., Nolan, T., and Whittington, J. "The Triple Aim: Care, Health, and Cost." *Health Affairs* 27 (2008): 759-769.

Black, B., Herr, K., Fine, P., Sanders, S., Tang, X., Bergen-Jackson, K., Titler, M., and Forcucci, C. "The Relationships Among Pain, Nonpain symptoms, and Quality of Life Measures in Older Adults with Cancer Receiving Hospice Care." *Pain Medicine* 12 (2011): 880-889.

Boston, J., Bradstock, A., and Eng, D., Eds. *Public Policy: Why Ethics Matter*. Canberra, Australia: Australian National University Press, n.d.

Campbell, L., Clauw, D., and Keefe, F. "Persistent Pain and Depression: A Biopsychosocial Perspective." *Biological Psychiatry* 54 (2003): 399-409.

Carlson, M., Barry, C., Cherlin, E., McCorkle, R., and Bradley, E. "Hospices' Enrollment Policies May Contribute to Underuse of Hospice Care in the United States." *Health Affairs 31* (2012): 2690-2698.

Carroll, A. "To be Sued Less, Doctors Should Consider Talking to Patients More." *The New York Times*, June 1, 2015. http://www.nytimes.com/2015/06/02/upshot/to-be-sued-less-doctors-should-talk-to-patients-more.html?rref=collection%2Ftimestopic%2FMedical%20Malpractice&action=click&contentCollection=health&region=stream&module=stream_unit&version=latest&contentPlacement=10&pgtype=collection&_r=1.

Centers for Medicare and Medicaid Services. "CAHPS Hospice Survey Fact Sheet." Last modified April 2015. http://www.hospicecahpssurvey.org/Documents/CAHPS_Hospice_Survey_Fact_Sheet_April_2015.pdf.

Centers for Medicare and Medicaid Services. "FY 2016 Hospice Payment Rate Update." Last modified July 2015. https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-07-31-2.html.

Centers for Medicare and Medicaid Services. "Hospice Payment System." Last modified October 2015. https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/hospice_pay_sys_fs.pdf.

Centers for Medicare and Medicaid Services. "Medicare Care Choices Model." Last modified October 2015. https://innovation.cms.gov/initiatives/Medicare-Care-Choices/.

Detsky, A. "What Patients Really Want from Healthcare." *Journal of American Medical Association 36* (2011): 2500-2501.

Edens, P., Harvey, C., and Gilden, K. "Developing and Financing a Palliative Care Program." *American Journal of Hospice and Palliative Medicine 25* (2008): 379-384.

Federal Register. "Medicare Program; FY 2016 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements." Last modified August 2015. https://www.federalregister.gov/articles/2015/08/06/2015-19033/medicare-program-fy-2016-hospice-wage-index-and-payment-rate-update-and-hospice-quality-reporting.

Gozalo, P., Plotzke, M., Mor, V., Miller, S., and Teno, J. "Changes in Medicare Costs With The Growth of Hospice Care in Nursing Homes." *The New England Journal of Medicine 372* (2015): 1823-1831.

Hartjes, T. "Making The Case for Palliative Care in Critical Care." *Critical Care Nursing Clinics of North America* 27 (2015): 289-295.

Hashe, J. "Being There for Those at End-of-Life." *The Pulse*, March 18, 2015. http://www.chattanoogapulse.com/beginnings/news/being-there-for-those-at-end-of-life/.

Henry J. Kaiser Family Foundation. "10 FAQs: Medicare's Role in End-of-Life Care." Last modified November 2015. http://files.kff.org/attachment/fact-sheet-10-faqs-medicares-role-in-end-of-life-care.

Hibbard, J., Stockard, J., and Tusler, M. "Hospital Performance Reports: Impacts on Quality, Market Share, and Reputation." *HealthAffairs 24* (2005): 1150-1160.

Himelstein, B., Hilden, J., Boldt, A., and Weissman, D. "Pediatric Palliative Care." *New England Journal of Medicine 350* (2004): 1752-1762.

Hobson, C. "Why Do Patients Want Treatment That Doesn't Work?" *The Conversation,* August 28, 2015. http://theconversation.com/why-do-patients-want-treatment-that-doesnt-work-42633.

Huskamp, H., Newhouse, J., Norcini, J., and Keating, N. "Variations in Patients' Hospice Costs." *Inquiry* 45 (2008): 232-244.

Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life.* Washington, DC: National Academies of Sciences, 2014. https://iom.nationalacademies.org/~/media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf.

Jacobson, P. "Medical Liability and The Culture of Technology." *Pew Project on Medical Liability,* September 22, 2004. http://www.pewtrusts.org/~/media/legacy/uploadedfiles/wwwpewtrustsorg/news/press_releases/medical_liability/medmal092204pdf.

Jennings, B., Ryndes, T., D'Onofrio, C., and Baily, M. "Access to Hospice Care: Expanding Boundaries, Overcoming Barriers." *The Hastings Center,* 2003.

http://www.thehastingscenter.org/uploadedFiles/Publications/Special_Reports/access_hospice_care.pdf.

Kang, T., Munson, D., Hwang, J., and Feudtner, C. "Integration of Palliative Care Into Care of Children with Serious Illness." *Pediatrics in Review* 35 (2014): 318-325.

Kelly, L., Bender, L., Harris, P., and Casarett, D. "The 'Comfortable Dying' Measure: How Patient Characteristics Affect Hospice Pain Management Quality Scores." *Journal of Palliative Medicine* 17 (2014): 721-724.

Lindley, L. "Health Care Reform and Concurrent Curative Care for Terminally Ill Children: A Policy Analysis." *Journal of Hospice and Palliative Nursing* 13 (2011): 81-88.

Linton, J. and Feudtner, C. "What Accounts for Differences or Disparities In Pediatric Palliative and End-of-life Care? A Systematic Review Focusing on Possible Multilevel Mechanisms." *Pediatrics* 122 (2008): 574-582.

Lutz, S. "The History of Hospice and Palliative Care." *Current Problems in Cancer* 35 (2011): 305-309.

Matsuyama, R., Reddy, S., and Smith, T. "Why Do Patients Choose Chemotherapy Near the End of Life? A Review of the Perspective of Those Facing Death From Cancer." *Journal of Clinical Oncology* 24 (2006): 3490-3496.

Medicare Payment Advisory Commission. "Hospice Service Payment System." Last modified March 2015. http://medpac.gov/documents/reports/chapter-12-hospice-services-(march-2015-report).pdf.

Medicare Payment Advisory Commission. "Reforming Medicare's Hospice Benefit." Last modified March 2009. http://www.medpac.gov/documents/reports/Mar09_Ch06.pdf.

Mello, M., Gawande, A., Studdert, D., and Chandra, A. "National Costs of The Medical Liability System." *Health Affairs* 29 (2010): 1569-1577.

Meyer, Harris. "Changing The Conversation in California About Care Near The End of Life. *Health Affairs* 30 (2011): 390-393.

Morden, N., Chang, C., Jacobsen, J., Berke, E., Bynum, J., Murray, K., and Goodman, D. "End-of-life Care for Medicare Beneficiaries With Cancer Is Highly Intensive Overall and Varies Widely." *Health Affairs* 31 (2012): 786-796.

Morrison, R., Penrod, J., Cassel, B., Caust-Ellenbogen, M., Litke, A., Spragens, L., and Meier, D. "Cost Savings Associated with US Hospital Palliative Care Consultation Programs." *Arch Intern Med* 168 (2008): 1783 -1790.

Nakhoda, Z. "End-of-life Care and the Medicare Hospice Benefit: The High Cost of End-of-life Care." *Journal of Financial Service Professionals* (2010): 24-28.

National Association for Home Care and Hospice. "CMS Proposed FY2016 Hospice Payment Rule Addresses Payment Reform, Aggregate Cap Changes, Diagnoses on Claims." Last modified May 2015. http://www.nahc.org/NAHCReport/nr150501_1/.

National Association for Home Care and Hospice. "Hospice Background." Last modified March 2016. http://www.nhpco.org/history-hospice-care.

National Association for Home Care and Hospice. "Key Legislation Affecting Home Care and Hospice." Last modified 2015. http://www.nahc.org/advocacy-policy/key-legislation-affecting-home-care-and-hospice/.

National Consensus Project. *Clinical Practice Guidelines for Quality Palliative Care.* Pittsburgh, PA: National Consensus Project for Quality Palliative Care, 2013. http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf.

National Hospice and Palliative Care Organization. "COPS - Planning for Success." n.d. http://www.nhpco.org/sites/default/files/public/regulatory/CoPs_Preamble_418-58.pdf.

National Hospice and Palliative Care Organization. "Hospice Care in America." Last modified 2013. http://www.nhpco.org/sites/default/files/public/Statistics_Research/2013_Facts_Figures.pdf.

National Hospice and Palliative Care Organization. "Hospice Item Set." Last modified November 2015. http://www.nhpco.org/quality/hospice-item-set-his.

National Hospice and Palliative Care Organization. "Quality Reporting." Last modified 2015. http://www.nhpco.org/quality-reporting.

Newman, D. "Do Patients Want More Care or Less?" *The New York Times*, April 4, 2012. http://well.blogs.nytimes.com/2012/04/04/do-patients-want-more-care-or-less/?_r=0.

Niethammer, D. *Speaking Honestly with Sick and Dying Children and Adolescents.* Translated by Victoria Hill. Baltimore: Johns Hopkins University Press, 2012.

Nyhan, B. "Why The 'Death Panel' Myth Won't Die: Misinformation in the Health Care Reform Debate." *The Forum* 8 (2010): 1 – 26.

Obermeyer, Z., Makar, M., Abujaber, S., Dominici, F., Block, S., and Cutler, D. "Association Between the Medicare Hospice Benefit and Health Care Utilization and Costs for Patients with Poor-Prognosis Cancer." *Journal of American Medical Association* 312 (2014): 1888-1896.

Ogundimu, T. "Concurrent Care: The Buzzword in Hospice Services." *Care Transformation Center*, September 29, 2015. https://www.advisory.com/research/care-transformation-center/care-transformation-center-blog/2015/09/hospice-concurrent-care-opportunity-assessment-2.

Palin, S. "Obama and The Bureaucratization of Health Care." *The Wall Street Journal*, September 8, 2009. http://www.wsj.com/articles/SB10001424052970203440104574400581157986024.

Passik, S., Ruggles, C., Brown, G., Snapp, J., Swinford, S., Gutgsell, T., and Kirsh, K. "Is There A Model for Demonstrating a Beneficial Financial Impact Of Initiating A Palliative Care Program By An Existing Hospice Program?" *Palliative and Supportive Care* 2 (2004): 419-423.

Pear, R. "New Medicare Rule Authorizes 'End-of-Life' Consultations." *The New York Times*, October 30, 2015. http://nyti.ms/1KLKbR2.

Plotzke, M., Christian, T., Teno, J., and Gozalo, P. "A Review of Claims-Based Quality Measures Used By The Centers for Medicare and Medicaid Services and Medicare Administrative Contractors to Monitor the Medicare Hospice Benefit." *Journal of Pain and Symptom Management* 51 (2016): 436-437.

Pyenson, B., Connor, S., Fitch, K., and Kinzbrunner, B. "Medicare Cost in Matched Hospice and Non-Hospice Cohorts." *Journal of Pain and Symptom Management* 28 (2004): 200-210.

Rady, M. and Johnson, D. "Admission to Intensive Care Unit at the End-of-life: Is It an Informed Decision? *Journal of Palliative Medicine* 18 (2004): 705-711.

Rotella, J. "The Devil is in the Denominator." *American Academy of Hospice and Palliative Medicine,* February 22, 2012. http://www.aahpm.org/apps/blog/?p=1239.

Schneck, A., Rokoske, F., Durham, D., Cagle, J., and Hanson, L. "The PEACE Project: Identification of Quality Measures for Hospice and Palliative Care." *Journal of Palliative Medicine* 13 (2010): 1451-1460.

Steinhauser, K., Christakis, N., Clipp, E., McNeilly, M., McIntyre, L., and Tulsky, J. "Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers." *Journal of American Medical Association* 284 (2000): 2476-2482.

Stevenson, D. and Huskamp, H. "Hospice Payment Reforms Are a Modest Step Forward, but More Changes are Needed." *HealthAffairs*, January 4, 2016. http://healthaffairs.org/blog/2016/01/04/hospice-payment-reforms-are-a-modest-step-forward-but-more-changes-are-needed/.

Stevenson, D. "Growing Pains for the Medicare Hospice Benefit." *New England Journal of Medicine* 367 (2012): 1683-1685.

Terry, M. "The New Quality Movement in Hospice and Palliative Care: Where Is It Going?" *Home Healthcare Nurse* 32 (2014): 65-66.

Thompson, J., Carlson, M., and Bradley, E. "US Hospice Industry Experienced Considerable Turbulence from Changes in Ownership, Growth, and Shift to For-Profit Status." *Health Affairs* 31 (2012): 1286-1247.

Von Gunten, C. "Financing Palliative Care." *Clinics in Geriatric Medicine* 20 (2004): 767-781.

Webb, J. and Kamal, A. "Integrating the Biopyschosocial Model into Quality Measures in Palliative Care: A Case for Improving the Hospice Item Set." *Journal of Pain and Symptom Management* 48 (2014): 1-2.

Weiner, R. "Sarah Palin Suggests Coin Conspiracy in Wisconsin Speech." *Huffington Post*, March 18, 2010. http://www.huffingtonpost.com/2009/11/09/sarah-palin-suggests-coin_n_350556.html.

Weireter, E. "NQF Endorses Palliative and End-of-Life Care Measures." *National Quality Forum*, February 14, 2012. https://www.qualityforum.org/News_And_Resources/Press_Releases/2012/NQF_Endorses_Palliative_and_End-of-Life_Care_Measures.aspx.

Wessman, B., Sona, C., and Schallom, M. “Improving Caregivers’ Perceptions Regarding Patient Goals of Care: End-of-life Issues for the Multidisciplinary Critical Care Team.” *Journal of Intensive Care Medicine* (2015): 1-9.

Whoriskey, P. and Keating, D. “Dying and Profits: The Evolution of Hospice.” *The Washington Post*, December 26, 2014. https://www.washingtonpost.com/business/economy/2014/12/26/a7d90438-692f-11e4-b053-65cea7903f2e_story.html.